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## **The impact of personal budgets on unpaid carers of older people**

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*Summary:* This paper focuses on the impact of a personal budget (PB) – either in the form of a direct payment (DP) or managed personal budget (MPB) – on the role of unpaid carers of older budget holders. Data were collected via postal survey of 1500 unpaid carers and semi-structured interviews with 31 carers.

*Findings:* Unpaid carers played a central role in supporting older budget holders irrespective of the type of budget received. The allocation of a PB may have decreased the amount of 'hands-on' care they provided, enabling them to do different things for and with the person cared for, but most did not relinquish direct involvement in care provision. Both kinds of PB provided greater flexibility to juggle caring tasks with other roles, such as childcare or paid employment. However, carers supporting DP users did experience higher levels of stress. This seemed linked to the additional responsibilities involved in administering the DP. Carers seemed relatively unsupported by their local Adult Social Care Department: the survey found that only 1 in 5 said they had ever received a carer assessment.

*Application:* The findings offer a detailed exploration of the impact of PBs on carers, suggesting that even in countries with relatively well-developed systems of support for carers such as England their impact remains overlooked. The paper may be of interest to social work practitioners, managers, academics and social work policy specialists working in countries that have, or are about to introduce, personal budgets or other forms of cash-for-care scheme.

## Background

Family carers are indispensable to the delivery of adult social care. In the UK approximately 6.5 million carers are estimated to save £119 billion a year in public expenditure by providing the great majority of care (Ungerson & Yeandle 2007, Buckner & Yeandle 2011). Though the lack of developed support for carers in some European countries is likely to mean substantial reliance on family care (Courtin, Jemai, & Mossialos 2014; Lamura, Mnich, Nolan, Wojszel, Krevers, Merstheneous, & Dohner 2008), even in more traditional welfare states carers are vital to the well-being of many frail, sick or disabled people. The campaigning organisation Carers UK (2014) estimates that 1.4 million people provide over 50 hours of unpaid care per week. The vital role of carers has been acknowledged by successive governments in England – for example, The Carers (Recognition and Services) Act (c. 12, 1995), the National Strategy for Carers (Department of Health, 1999), the Carers Equal Opportunities Act (c.15, 2004) and the Refreshed Carers Strategy (Her Majesty's Government, 2010). However, The Care Act (c.23, 2014) has, for the first time, placed legal duties on local authorities to attend to the well-being of carers, by codifying carers' legal rights to an assessment of their needs by their local authority, and provides a significant context for this paper.

Carers UK (2014), King (2013), and Rand and Malley (2014) have variously drawn attention to the experiences of carers, the impact of caring on well-being, employment, their needs, and how these can be acknowledged and addressed by the National Health Service (NHS) and social care organisations. Studies have also demonstrated an association between care-giving and stress, exhaustion and development of anxieties which can impact negatively on well-being and health (Hirst 2004). Meta-analyses of research have highlighted the impact of the stresses associated with providing care (e.g. end of life care at home: Funk, Stajduher, Toye, Aoun, Grande & Todd, 2010; or for care following a stroke: Greenwood & Mackenzie, 2010).

Carer burden and breakdown are common causes of moves to hospital or permanent residential care of disabled individuals (Zarit, Todd & Zarit, 1986). As the focus of this paper is on carers of older people, it is also important to highlight that many carers are older people themselves. Carers UK (2014) estimates that 1.3 million carers (20% of carers in the UK) are 65 years of age or older.

Given the complex relationships between caring and carer health, well-being and stress, the implementation of the 'personalisation agenda' – specifically the introduction of personal budgets (PBs) can reasonably be expected to have a significant impact on carers which deserves closer attention.

In England, PBs describe an arrangement whereby a sum of money, (the amount calculated following an assessment of need by a social worker or care manager) is allocated to people eligible for social care to pay for their care and support. It can be taken in a number of ways, but the most common are a 'Direct Payment' (DP) or a 'Managed Personal Budget' (MPB). DPs are payments made directly into a dedicated bank account controlled by a person with care needs (or their legal proxy) who can choose the kinds of support they want to have and exercise control over the way the money is spent on meeting their needs. MPBs are managed and spent on behalf of a person eligible for social care by a nominated third party – a relative, the local social work/care management team or a commissioned third sector service.

At the present time (end 2015), there is no settled consensus in research and policy communities about the value or effectiveness of PBs. Advocates emphasise the ways in which DPs confer greater choice and control over services and thereby greater independence (Leadbeater 2004; Duffy 2006, 2008, 2014) Critics argue that they represent a shift in responsibility for arranging and providing care from the state towards often vulnerable

individuals (Ferguson 2007); that the budget amounts are insufficient (Beresford 2009a, 2009b, 2011); and introduce unwelcome consumerist, neo-liberal values into an important part of the post-war welfare state (Clarke, 2005, 2007; Clarke, Smith & Vidler, 2006, Clarke, Newman, & Westmarland 2008; Daly, 2012).

At a more micro-level, Leece (2010) and Scourfield (2010) have considered the ways in which the nature of relationships between budget holder, paid and unpaid carers may change with the introduction of the PB. There has also been some research on outcomes. Moran, Arksey, Glendinning, Jones, Netten and Raibee (2012) found that possession of a budget as a DP had a positive impact on carers. Despite the additional responsibilities arising from managing or helping to manage the DP, it enabled changes to the nature of carer responsibilities, partly through enhanced flexibility of care provision, enabling needs of both carer and the disabled person to be addressed. Later studies by Glendinning, Mitchell and Brooks (2013) and Brooks Mitchell and Glendinning (2016) contained less positive findings. Whilst concluding that carers were centrally involved in assessment and support planning for DP recipients, they found that less attention was paid to carer needs in their own right, and that local authorities continued not to integrate carer assessment practices into new personalisation processes. Rand and Malley (2014) also explored carers' perceptions of their roles, their experiences, and their quality of life, though not specifically in relation to DPs and MPBs. Their findings, however, reaffirmed that lack of support was especially likely to have a negative impact on carers' quality of life.

Less attention has been paid to the impact of DPs and MPBs on carers of older people. This is an important topic for investigation. In England older people constitute the largest proportion of adult social care service users and consume over half of all personal social services expenditure (Health and Social Care Information Centre [HSCIS], 2013). Furthermore, evidence

suggests older people do not achieve such good outcomes through PBs as younger service users (Glendinning et al., 2008; Woolham and Benton 2013): findings that have significance to this paper, though its main objective is to examine the impact of PBs – whether as DPs or MPBs, on carers of older PB users. This is a relatively overlooked topic in the UK where most research has focused on the impacts upon recipients of budgets themselves.

## Methods

### Research design and methods

The study adopted a mixed method design, using a postal survey of 1500 randomly selected carers of older DP and MPB users in three local authority sites and 31 interviews with carers. The three sites were opportunistically selected. Two were shire counties – one in the south of England, one in the north-west, and the third was a unitary council in the north-east of England. Eligibility criteria were that carers should be caring for someone aged 75 or older who lived in their own home (or with the carer) or in sheltered housing, and that they should be paying for care services through a DP or MPB.

### Instruments

The postal survey questionnaire was 12 pages long and contained 31 questions, including 5 ‘open’ questions in five sections. In the first section, questions elicited carer views about the process of finding out about the personal budget (whether DP or MPB) and how the person used their budget. This first section was designed to mirror as far as possible typical stages in an assessment and support planning process followed by social workers or care managers in arranging the PB. Section two focused on any difficulties experienced in getting the PB set up and operationalized and the help available to overcome these difficulties. Section three sought information about the experiences of carers of ‘living with the PB’ – and the fourth section was

designed to collect information about the impact of the budget. This section included a single validated scale – the Zarit Care Giver Burden Scale, (Zarit, Reever and Bach-Peterson, 1980) to measure carer stress. The scale consists of a 22 question, 5 item scale, scored from 0 to 88 with higher scores representing higher levels of stress. A fifth, final section collected demographic information. In this paper, we have drawn on responses to 13 questions from all sections of this survey.

Survey data were analysed using SPSS (version 22) statistical software. The survey mailshot and two reminders were administered directly by the local authorities to ensure compliance with the Data Protection Act and confidentiality.

#### Interviews

Interviews used a semi-structured questionnaire and were conducted either in the carer's home or by telephone. Interviewees were randomly selected from a larger, self-selecting group who had provided their contact details on the survey questionnaire in response to an invitation to take part in a follow-up interview. The length of the interview varied from 20 minutes to over one hour. Each was digitally recorded with consent and subsequently fully transcribed and entered into NVIVO computer software. Framework Analysis (Ritchie & Spencer, 1994) was used by a member of the research team to code and inductively analyse the data (Hodkinson, 2008) to identify underlying themes. 'Framework' provided a clearly defined set of procedures to abstract and conceptualise themes, which combined rigour and flexibility needed to analyse the dataset. Data were subsequently analysed by another team member enabling independent checking and validation of emergent themes. Where direct quotations are used in the findings section below these are used to illustrate particular issues that emerge from the analysis.

Carers of DP users		Carers of MPB users	
Intended sample size	750	Intended sample size	750
Actual sample size	153	Actual sample size	1,347
Exclusions	26	Exclusions	50
Response	53 (42%)	Response	240 (19%)

**Table 1. Details of samples included in the survey.**

Data collection was not straightforward. Though the intended sample size was achieved, the distribution of carers identified in each sample was very different, as can be seen in Table 1. Not all local authorities were able to identify the required number of carers of DP users, either because they did not collect the information or because the information systems used were unable to accurately identify carers of DP users. It was not possible to obtain demographic information about all sample members to assess possible response bias for similar reasons. The study set out to exclude carers who had been formally allocated a PB to spend on behalf of the person they were caring for since other research has focused on this group specifically (Mitchell, Brooks and Glendinning 2013; Laybourne, Jepson, Robotham and Cyharova 2015).

A relatively large proportion of exclusions were identified in each group. These largely reflected the variable level of accuracy of local records in some sites. There seemed to be three main reasons for the exclusions. Some respondents said they were no longer providing care because the cared-for person had died, moved to a care home, or been hospitalised. Questionnaires were also returned uncompleted with a note to say that the addressee was no longer at the address on file. Finally, some carers of people who were using a MPB said they were unaware that the person they cared for was receiving a MPB and therefore felt unable to take part. In total 293 carers responded, an overall response rate of 21%.



	Carers of DP users	Carers of MPB users
Mean age	59.2 yrs.	63.9 yrs.
Gender		
<i>Male</i>	13 (28%)	66 (34%)
<i>Female</i>	33 (72%)	128 (66%)
Ethnic background		
<i>White</i>	50 (96%)	231 (99%)
<i>Asian</i>	1 (2%)	0
<i>Black</i>	0	1 (<1%)
<i>Other</i>	1 (2%)	2 (1%)
Relationship to caree		
<i>Spouse/partner</i>	10 (19%)	74 (32%)
<i>Son/daughter</i>	35 (67%)	118 (50%)
<i>Sibling</i>	1 (2%)	6 (3%)
<i>Other relative/friend/neighbour</i>	6 (12%)	36 (16%)
Living with caree		
<i>Yes</i>	15 (29%)	112 (48%)
<i>No</i>	36 (71%)	121 (52%)

**Table 2. Demographic profile of respondents.**

Comparing the demographic profiles, carers of DP users tended to be younger (an independent samples T test of  $p=0.012$  confirmed this to be significant) and more likely to be female. Both groups were overwhelmingly white: minority ethnic groups were under-represented (the overall proportion of minority ethnic groups across the three sites in the general population was <7% (Office for National Statistics [ONS], 2011). This may have reflected lower take-up of services by local minority groups (and consequently sampling error) or response bias, or that there were disproportionately fewer carers from minority ethnic groups. Carers of DP users were also more likely to be sons or daughters of the budget holder and much less likely to be

living at the budget holder's address than spouse carers. Differences between carers living /not living with the cared for person were significant ( $X^2$   $p=0.015$ ).

## Findings

The findings presented in this next section are offered sequentially and intended to reflect as far as possible key stages of the local authority processes for the deployment of PBs (whether PBs or DPs). The first group of findings cover the feelings of carers about PBs from the outset, and include their views about the information provided about them. The second group reflect the recollection of carers about their level of involvement in support planning, and whether their own needs as carers had been sufficiently taken into account. Survey findings about the level of carer involvement after support plans had been set up and services commissioned, and the impact they may have had on carers are then presented.

### *Feeling about personal budgets when first told about them*

As can be seen in Table 3, when first told about PBs and DPs, although a proportion of carers from both groups was keen for the person they cared for to have a personal budget the proportion was much higher amongst carers of people who went on to be DP users: carers of MPB users seemed much less enthusiastic.

	Carers of DP users	Carers of MPB users
I didn't want the person I care for to have a personal budget	2 (4%)	23 (11%)
wasn't sure I wanted the person I care for to have a personal budget	23 (11%)	70 (34%)
I was keen for the person I care for to have a personal budget	37 (74%)	95 (46%)
Some other feeling	3 (6%)	20 (10%)

**Table 3. Which of the following best describes your feelings when you were told about PBs? (n=258,  $X^2=13.14$ , df=3, p=0.004).**

Some carers explained the reasons for their response in an open question in the survey. Among carers of MPB users, the majority of comments indicated that until being invited to take part in the survey, the carer had not known about PBs:

*'I don't know anything about personal budgets. Social Services did an assessment and carers to assist in getting my wife showered and dressed at 7.00am and ready for bed at 19.00pm. They pay (the care agency) for those carers. We do not know how much that costs. It has never been mentioned'* [Survey respondent].

However, other carers, though told about PBs, said they had not been given any information about them to enable them to form a view:

*'...it was never explained fully why when and how it would be implemented and what advantages if any would be attained by having one'* [Survey respondent].

Carers who were positive about DPs from the outset emphasised opportunities for flexibility, control and choice not previously available, while others were happy for the person they cared for to have a MPB:

*'I felt social services were the more qualified to handle the budget and could steer me in the right direction'* [Survey respondent].

From interview data, one or two carers, though initially keen to try PBs, did not find their experience matched their expectations:

*"....it started to get quite complex because we did actually have a carer we wanted to employ but you have the difficulty then of managing that and I think that, to me, is where, it's a difficulty for people because you've got all the employment issues, you've got holidays, you've got sickness, you've got training, they've got all sorts of different things that even me, running the organisation that I do... wouldn't have the time to do that".* [Interviewee].

### *Needs for information*

It was clear from interviews with carers that some had concerns about the amount of information, and the quality of what was provided about PBs and DPs. Many carers felt they had received very limited information.

Some of those who felt the amount of information had been acceptable qualified their responses. One interviewee had previously worked for a local authority and felt that this conferred necessary background knowledge, and others expressed confidence about taking on the management of the PB because of their occupational background. However, they felt those they cared for would not have understood the information provided:

*Interviewer: "So when you started making enquiries was the information that you got fairly easy to understand?"*

*Carer: "I think so, for me, yes, but again elderly people and bearing in mind my mum's 88, they wouldn't have a chance".*

*Interviewer: "So the information you got wasn't really designed for older people?"*

*Carer: "There's too much of it and too many forms and that" [Interviewee].*

Carers also noted that a face-to-face visit by a care manager was often helpful in explaining how PBs worked, usefully augmenting written information.

Shortcomings within the information provided were mentioned. It was particularly apparent that carers of older people with a MPB had encountered a lack of transparency which may have prevented them, or the person they cared for, from exercising choice and trying a DP:

*Carer: "I wasn't really aware that it was an option until my mother was having her finances reviewed.*

*Interviewer: "OK, and that was done by Social Services or an organisation like Age Concern?" (sic).*

*Carer: "Someone from Age Concern came out...and he said 'you could always sort of finance it yourself, do it yourself, instead of paying an agency' but I wasn't really aware of how easy it was to do, to be honest with you."*

*Interviewer: "No, so what were the choices offered to you then...?"*

*Carer: "What happened was I had carers (care workers) in place that I wasn't happy with...so when this gentleman mentioned that we could go down that route, I rang social services and had a chat with them and a lady came out who assessed my mum and dad and said yes, it would be a viable thing to do."*  
*[Interviewee].*

However, it seemed likely that in other cases, care managers and social workers may have been exercising reasonable professional judgement and discretion, taking into account the capacity of the older person and the circumstances of their carer: their health problems, pre-existing levels of stress and degree of well-being:

*Carer: "There were two people that came to see us, two people together who came to talk to us and they actually said, 'oh no you wouldn't want to be doing this yourself because it would be too difficult.' Since she's been here nobody has ever said we could have direct payment organised, no one has actually ever said that".*

*Interviewer: "That's interesting; I guess there are pros and cons".*

*Carer: "Yes."*

*Interviewer: "You probably know - direct payments can give more flexibility and freedom but there's also more responsibility entailed".*

*Carer: "Yeah, I feel totally overwhelmed. I have a 14 year old granddaughter who lives with me and was 10 when [name] moved in, my husband had radio-chemotherapy last year, so I've got a lot of responsibilities and I couldn't actually face any more". [Interviewee].*

Occasionally, the *failure* of a care manager/social worker to exercise discretion created peculiar anomalies. For example, one carer said that his wife, previously diagnosed with dementia, had been given a DP rather than him. In his view, this was a mistake as she was completely unable to manage this, and he had to do it anyway.

Lack of information about PBs at the start of the process was not the only concern of carers. Poor information sharing throughout the assessment and support planning processes was

often mentioned. Carers drew attention to poor communication between different support organisations and the local authority, or within the authority itself:

*‘Direct Payments, which is what my mother has, was confusing at first, as in the explanation and what exactly it could be used for, when and how it would be paid – it’s offered under enormous stress (for the family) and so the info (information) is difficult to digest. Far too many ‘experts’ with a hand in the pie, in my opinion – lots of facets picked up by different people, honestly, it’s a nightmare!’* [Survey respondent].

Some carers reported being unable to obtain information about the best care agency to meet the specific needs of the person they cared for because care managers or social workers told them this was ‘commercially sensitive’. Other practitioners offered discrete information to help the budget holder and carer:

*“...they were very circumspect about it...they can’t actually say it out loud, but the social work assistant that came to do the assessment, she said something like ‘Oh, right, OK, (named care agency) are like Marks and Spencer whereas these other care agencies are like Sainsbury’s or something’.* [Survey respondent].

Some carers reported that they had received too much, or contradictory information, or information that, when acted on, was found wanting. Referring to experiences with an agency providing care for her mother, one carer said:

*“They’ve got an emergency number and you ring that and nobody answers it. So, I am a little bit unhappy with the way they work. Well, they do answer it sometimes - it depends who’s on call. But then I’ve been told, “it’s for staff only, that number,” and*

*then I've been told, "no, it's not," then I've been told, "don't ring it after 11 o'clock," and "what can we do anyway?" Well, if something bad is happening, I need to know there's somebody there - even if you just talk to me". [Interviewee].*

### *Involvement in support plans*

Carers were usually involved in the assessment of need carried out by a social care professional (usually a care manager or social worker) that preceded the decision made about the indicative size of the budget, and a smaller proportion, though still a majority in both groups, was subsequently involved in constructing the support plan, as evident in Table 4.

	Carers of DP users	Carers of MPB users
Were you involved in the assessment in any way?		
Yes	47 (89%)	175 (77%)
No/not sure	6 (11%)	53 (23%)
Were you involved in helping write the support plan?		
Yes	29 (62%)	116 (55%)
No/not sure	18 (38%)	97 (46%)
Were you offered a separate assessment of your needs, as a carer?		
Yes	11 (21%)	41 (18%)
No/not sure	41 (79%)	191 (82%)

**Table 4. Unpaid carers involvement in assessment (n=281  $\chi^2= 483$ , df=1, p=0.487); support planning (n=260  $\chi^2= 819$ , df=1, p=0.366) and proportion having a separate assessment of their needs as a carer (n=284,  $\chi^2 =2.74$ ,df=2, p=0.254).**

However, despite close involvement in assessment and support planning, as Table 4 further shows, only about one fifth (20%) of carers from either group said they remembered ever having been offered a separate assessment of their needs as carers. A relatively high



proportion from both groups answered that they had not or were unsure if they had been offered an assessment. This seemed to reflect a situation in which assessment and support planning activity were exclusively focused on the older cared-for person, and a sense in which local authority processes were unclear; so, for example, casually expressed questions by the care manager might subsequently be recalled as possibly forming part of such an assessment.

The failure to carry out a separate carer assessment had other consequences for both carer and person cared for:

*“I need more help probably now. And of course, it’s all to do with mum in a way, because when Social Services came they ask my mum the questions. If she says that she doesn’t want the help; that can go against trying to get the help, because they’re obviously interested in what the client’s saying; it’s more important probably than the carer. So if we get reassessed and my mum says she’s fine, then that could go against the assessment a little bit, which is what happened last time”. [Interviewee].*

Carers also found themselves ‘troubleshooting’ when problems occurred in getting care and support commissioned and underway. As Table 5 shows, this was the case with both groups: there was no statistically significant difference between them.

	Carers of DP users	Carers of MPB users
<i>Very involved</i>	15 (29%)	39 (20%)
<i>Quite involved</i>	4 (8%)	20 (10%)
<i>Not involved</i>	5 (10%)	23 (12%)
<i>Not applicable (no problems)</i>	27 (53%)	117 (59%)

**Table 5. If there have been any problems in getting services and support going with the Personal Budget, how involved have you been in trying to sort these out? (n=250,  $\chi^2=2.36$ , df=3, p=0.499).**

About a third of carers interviewed reported difficulties that required their intervention.

The first of these difficulties was in relation to the employment of care workers through a DP and the need to understand and keep abreast of administration or paperwork. A number of carers suggested that although they did not necessarily find this difficult, they did feel that it was necessary for them to be ‘on top of it’ all the time.

The second referred to difficulties in obtaining care services and adjusting support packages. Though some of the ‘troubleshooting’ here related to temporary problems that might be expected to occur in a new support package and which could be quickly identified and fixed, this was not always the case. Some interviewees reported that the person for whom they cared had fluctuating health, and though finding a DP helpful in paying for additional care when needed, others found that the purchasing power it conferred did not address the need for service flexibility:

*“No, it never worked smoothly. It still doesn’t work smoothly. There’s always problems with it because the amount of care she needed changed and the type of care she needed changed over time anyway. The care agency we use, it’s quite difficult...You’re*

*always having to change things. She can't have her tea at five o'clock. It has to be half past four, which is a bit early for her. They were doing pop-ins at night which was half past eight at night, which was way too early, but they didn't have anyone until later...There's always teething problems - well, it's not teething problems. There's always problems with it, to be honest". [Interviewee].*

A third category of responses related to worries about the adequacy of funding and anxiety about whether funding would be sufficient to meet future needs. As the needs of most of those cared for increased, so did worry about whether the budget would be sufficient or whether financial reassessments might even lead to a reduction in budget size because of 'austerity'.

Carers further reported having to resolve confusion about how, and on what, the PB could be spent.

### *Carer involvement after support plans were operationalized*

One reason some carers (and some social work practitioners) decided not to opt for a DP was concern about the amount of paperwork or administration. For MPB users, much of this would be managed by the local authority. DP users were potentially responsible not only for paying bills but also recruiting and employing carer workers and complying with employment legislation. Though some support was provided by third sector organisations commissioned by the local authority, some carers preferred to make the budget go further by doing the paperwork themselves, thereby taking on more responsibility and work for those they cared for.

	Carers of DP users	Carers of MPB users
<i>The person I care for deals with all paperwork alone</i>	1 (2%)	5 (2%)
<i>I help the person I care for with the paperwork or do it all on their behalf</i>	41 (80%)	134 (61%)
<i>Someone else deals with all the paperwork</i>	8 (16%)	54 (24%)
<i>Not sure</i>	1 (2%)	28 (13%)

**Table 6. Who sorts out any paperwork associated with the personal budget? (n=272  $\chi^2=8.38$ , df=3, p=0.039).**

In this study, the ‘budget holder’ was either the older person in receipt of care, directly, in the form of a DP, or a local authority operational team, as a MPB. (Despite an intention to exclude carers who held the budget, a small proportion of carers may nonetheless have been designated budget holders. Although it was not possible to conclusively establish how many carers held the budget because not all sites could produce this data, a survey question asked how the cared-for person’s budget was managed - this suggested that the carer was the designated budget holder in about 11% of cases). However, despite ‘ownership’ of the DP resting with the older person, in the overwhelming majority of cases, only one carer felt that this was managed by the older person alone and without help from someone else. In practice, over 80% of carers of DP users said that they helped or dealt completely with any paperwork associated with the budget. The corresponding figure for MPB users was also high at 61%.

One paradoxical effect of self-management amongst DP users seemed to be a diminution of personalisation by the local authority. Some carers felt that as contact was more infrequent, and with different people on each occasion, the professionals with whom they spoke did not ‘know’ them and it was necessary to provide contextual information on each occasion:

*“In doing things more for yourself, managing things yourselves, you’ve lost some of the contact with the social services assessment people from a care point of view because you were much more in control of things yourself. As a consequence of that, when you did need that connection with them, it was harder to get things going again...I suspect if we’d been more in touch with social services on the various assessment teams...they would have appreciated that a 93 year old that was falling a lot needed more care and it would have to be part of the budget. Whereas, we tended to be speaking to somebody who didn’t know her, who didn’t know me.” [Survey respondent].*

### *Impact on carers*

The provision of a DP, whether managed by the older person or, as seemed to be the case, more usually by the carer, might reasonably be expected to have an impact on carers. Data from the survey and from follow-up interviews suggested that the nature of this impact was not always straightforward or uniform.

	<b>Carers of DP users</b>	<b>Carers of MPB users</b>
I now provide more care and support	11 (21%)	17 (8%)
I provide the same amount of care and support	28 (54%)	117 (56%)
I now provide less care and support	11 (21%)	57 (27%)
Not sure/too early to say	2 (4%)	20 (10%)

**Table 7. Has the Personal Budget of the person you care for made any difference to how much care and support you provide? (n=263,  $X^2= 8.87$ , df=3 p=0.031).**

In most cases, and for both groups of carers, the budget made no difference to the amount of support provided, but carers of DP users were more likely to say they provided more, and carers of MPB users less, care.

Interviewed carers were asked about the impact of the PB on their own life. For some, a DP had been a solution to worrying and seemingly intractable problems when the cared for person received 'traditionally' arranged services:

*"...they were constantly neglecting him and I couldn't be there 24/7 and to find out that ...they hadn't come when they said they were going to come, they hadn't given him the food...they've left the door unlocked so it's been open all night...The catalogue of things was a nightmare because I couldn't be there all the time to care as I wanted to. The fact now that I've got somebody I can trust, it's a doddle".* [Interviewee].

But for carers of other DP users, the budget created new problems; for example, because of service fragmentation, worries about making the budget stretch far enough or poor communication:

*"I mean, I presume they must keep case notes and all the rest of it, but presumably they don't refer to them before they actually contact you and make these requests for information or whatever. So it's very, very frustrating ..."* [Interviewee].

Carers of DP users also referred to the ways in which their role as carers affected their ability to maintain a social life outside of their caring role. One carer paid a particularly high price for their caring responsibilities:

*“I had a relationship, a 10 year relationship...but the pressures of my mum have increased year on year really and it meant the end of that relationship and that caused me to have severe depression which I’m just coming out of now, really. So overall a care plan doesn’t cover all eventualities”. [Interviewee].*

Though carers saw DPs as a means of securing better quality care for those for their relative, and it did lead to welcome changes in the kinds of care that they provided as carers, interviewees felt it led to more, not less work; some of which was in the form of additional paperwork and responsibility. However, for some carers, DPs also offered welcomed opportunities for greater flexibility, and the exercise of greater control over the quality of care provided.

### *Carer stress*

The study used the Zarit Care-Giver Burden Scale (Zarit et al. 1980) to compare levels of stress amongst both groups (DP and MPB). Only a minority of carers from either group acknowledged feelings of stress arising from their role. Mean scores were only marginally different: for carers of DP and MPB users the mean scores were 37.3 and 35.8 respectively. Though not statistically significant, there were noticeable differences in the distribution of the scores, as can be seen in Table 8.

	<b>Carers of DP users</b>	<b>Carers of MPB users</b>
Little or no burden	9 (20%)	47 (23%)
Mild to moderate burden	15 (33%)	89 (43%)
Moderate to severe burden	16 (36%)	52 (25%)
Severe burden	5 (11%)	21 (10%)

**Table 8. Zarit Care-Giver burden Score profiles (n=254,  $X^2=2.49$ , df=3, p=0.476).**

Table 8 shows that a higher proportion of carers of DP users were experiencing a moderate to severe or severe burden compared to carers of MPB users. Whilst 47% of carers of DP users experienced a moderate to severe, or severe burden, the corresponding figure for carers of MPB users was 35%.

## Discussion

Specific questions emerged from the findings. These include how DPs are actually managed, the relative ‘invisibility’ of carer needs despite the very significant role they played in managing budgets and ‘troubleshooting’ on behalf of those they care for, as well as both financial and non-financial costs to carers. They highlight the importance of information sharing but expose some of the difficulties experienced by carers in obtaining information. Finally, they also provide a different perspective on the role of care managers and social workers in relation to the exercise of discretion and judgement.

### *Who actually manages the direct payment?*

In the overwhelming majority of cases, where the DP was held by the older person, in practice it was managed on a day-to-day basis by their carer. This is consistent with other studies, most



recently in Glendinning Mitchell and Brooks (2014), and suggests local authorities may often overlook the fact that many older people with eligible social care needs cannot or do not wish to manage a DP. This may be because the present Government's preference is for people eligible for care to receive a DP with which to purchase care or support (Department of Health, 2010a). The proportion of adults (of all ages) choosing DPs remains small – 19% in 2014, and local authorities continue to be judged by central government on the numbers of social care users who receive one. Performance indicators (HSCI, 2014) will continue to create pressure to increase the number of DP users to improve performance in relation to this indicator. Our findings lend support to the work of those who have argued that current English personalisation policy has been influenced predominantly by the requirements of younger service users and is based upon values that do not work well for most older people (Barnes, 2011; Lloyd, 2010; Orellana, 2010; Woolham et al., 2015). Policy change may be needed to reflect the needs, wishes and circumstances of older people. New obligations within the Care Act (2014) for local authorities to assess carers' needs address these concerns only in part.

### *Carers assessments*

Though involvement of carers in setting up, commissioning and managing the PB was considerable, most had not received a separate assessment of their needs. Moriarty, Manthorpe, Cornes and Hussein (2014) and Moriarty, Manthorpe, and Cornes (2015) have suggested that most carers do not receive social care support. Glendinning et al., (2013) and Mitchell et al., (2013) each suggest that local authority social care professionals generally assumed that carers would manage the budget if the cared for person was unable to do so themselves. The Care Act (2014) places new duties on local authorities to ensure that carers are properly assessed on the appearance of need. Our findings suggest that the three sites participating in this study may be starting from a low base-line as carer assessments did not seem to have been a particular priority. Given the shrinking resource base in English local

authorities due to continuing austerity policies, and if these three sites are typical, fulfilling these new duties may be challenging. Others have also drawn attention to a lack of convergence or integration of carer assessment practices into new personalisation processes as well as to problems in reconciling carer and disabled people's assessments (Glendinning et al., 2013) along with a tendency amongst local authorities to consider carers as additional resources or co-workers rather than co-clients (Glendinning et al., 2014).

### *Information sharing and personalisation*

To be able to construct support plans to meet eligible needs, carers and those cared for need reliable, personalised information (Baxter and Glendinning, 2008); but carers also can experience difficulties in finding out about services that could help them (Moriarty et al., 2015). Several carers who were interviewed drew attention to the inability of local authorities to provide this. Carers of DP users were sometimes unclear about on what they could, and could not, spend their budget, and carers of MPB users – those who were *aware* there was a MPB – usually did not know the budget amount or how this had been determined.

Carers often wanted support and advice for themselves and the person they cared for in order to make important decisions about which care provider to choose, but found that professionals were unable or unwilling to provide this because they believed, or had been instructed, that the information was commercially sensitive. Concerns were also expressed about the failure of the local authorities or other support organisations to process information given to them by the carer or the budget holder accurately, to share information with one another, or to retain information. Several carers commented that they felt that they had to go back to 'square one' each time they needed to contact their CASSR because the person they had spoken to did not know them or the person for whom they cared. Significant investment in infrastructure and training would be needed by local authorities to improve the

personalisation of information, but this is likely to be difficult to achieve within the context of the austerity policies of the present government (Brookes, Callahan, Netten and Fox, 2015).

### *Non- financial costs and benefits to carers*

Most carers were initially enthusiastic about PBs since they offered greater opportunities to tailor services and support, giving carers better opportunities to co-ordinate paid care with what they themselves provided and to have greater control over care quality. Though some carers felt PBs had been very useful in achieving these things, others identified concerns about paperwork, the lack of availability of local services as well as difficulties in choosing the right providers; concerns about budget amounts; the number of people with whom they had to deal as 'proxy' budget holders, and a sense of detachment from the local authorities as cases were not kept open but re-allocated each time. These may have contributed to higher stress levels amongst carers of DP users. Stress levels amongst carers of MPB users were also high for a smaller but still substantial proportion. However, causes of stress for this group seemed more likely to arise from difficulties in co-ordinating the care and support and in seeking redress when care quality was unacceptable.

### *The exercise of professional judgement by practitioners*

Social workers and social care professionals have been criticised by politicians and advocates of PBs and DPs for their failure to relinquish power to service users (Smith, 2010). Our findings suggest a more complex picture. 'Practice wisdom', professional judgement or 'street level bureaucracy' amongst front-line practitioners (Ellis, 2007), may have benign or even positive consequences for the older service user and their carer if based on realistic assessments of the service user or carer's capacity to cope with the additional responsibilities and workload involved with DPs. The provision of 'off the record' information about care agencies also helped inform choice. This exercise of benign professional discretion has also been noted in

other studies in relation to practitioner recording of carer roles (Mitchell et al. 2013). Carers of DP users in our study were much less likely to be living at the same address as the cared-for person and were more likely to be their son or daughter than their spouse. This may have been one consequence of this discretionary role.

However, our study also found that many carers of MPB users were unaware of the existence of a PB and a small number of carers felt that, had they been given different information, they and the person they cared for may have made different decisions – and sometimes did, when this information came to light. This suggests that professional discretion was also sometimes based on erroneous assumptions rather than on what the older person or their carer might actually want. However, though the withholding of information to retain power cannot be excluded as a possible explanation, other motives seemed equally likely, including a desire to protect older people and their carers from additional worry and stress, to take the easier path because of workload pressures, a response to resolve a lack of clarity in local policy and procedures, poor supervision practices, poorly developed information systems to support personalised practice, or a combination of these things. The underlying reasons for professionals' decisions to promote or not promote the DP option with carers were complex and further research might lead to a better understanding of underlying factors.

### *Limitations*

This paper is based on findings from a survey of carers of older people who were PB users in three local authorities, and follow up interviews with a much smaller number of carer participants. Though overall response rates to the postal survey were adequate for a survey of this kind, the two samples obtained were not of equal size, and demographic data on members of the sample could not be obtained from all of the local authorities, preventing any assessment of sampling error or response bias. Further research based on a larger number of

local authorities with a better balance between DP and MPB participants and with the availability of demographic information on sample members may have improved the reliability of the findings. Follow up interviews were conducted with a self-selected group of carers and, though the final selection process was randomised, there is some possibility that interview data was unrepresentative. Therefore, a little caution may be needed in assessing the significance of our findings.

## **Conclusions**

Our study presents an emerging and complex picture of the impact of PBs and DPs on carers. Although policies underpinning the introduction of PBs in England have started to recognise the need to support carers as well as service users, there has been relatively limited research on their impact on carers.

The policy drive to increase the use of DPs, in particular, amongst older social care users in England requires the transfer of responsibility for managing care away from the state and onto carers of service users. Despite the new statutory responsibility for local authorities to assess carer needs offered in the Care Act this may also represent an unwelcome shift towards a re-definition of citizenship (Clarke, 2005; Daly, 2012) in which responsibilities are talked 'up' and social 'rights' - to high quality, person-centred care - are contingent on the entrepreneurial skills of carers. Unsurprisingly, our study found that many carers were happy to accept such responsibilities - even unacknowledged by their local authorities - as a price worth paying for improving the quality of care and support for someone they loved. However, we also found that these carers were often inadequately supported to fully take on such responsibilities. We see no immediate prospect of any re-emergence of a new policy consensus that re-balances these rights and responsibilities and therefore suggest further research is needed to explore

those factors that cause greatest stress for carers who decide to manage PBs so local authorities can offer targeted forms of support to address them.

## **Ethics**

Ethical approval for this study was given by the Social Care Research Ethics Committee (England) ref. 12/IEC08/0013.

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